

***Public Health Data Standards Consortium
Privacy, Confidentiality & Data Sharing Work Group
December 9, 2002 12:30 ET***

Chair:

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Members:

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Introductions of workgroup members.

Chair for the Workgroup:

John Lawniczak has agreed to chair the group. Members concur with the appointment. No other volunteers came forward.

Discussion and development of the PCDS Workgroup charter

Members had an opportunity to review the charter document prior to the call. Some members were curious as to why the workgroup is being formed at this time. The basis for this workgroup was developed at the Steering Committee meeting last March. A subsequent conference call of the Steering committee indicated that this workgroup was still necessary and that members were willing to commit to putting the group together. John agreed to chair the group, which provided an ability to move forward.

Members also wondered about whether the list of functions was the result of previous discussions and was already consensus based. The list of functions was developed from work done by other workgroups and ideas expressed at the annual meeting. It was compiled as a starting document for this group and can be changed or supplemented as the group desires. Some concerns were expressed that the language is quite broad and would need to be prioritized. It was felt that the charter can be broad while the work plan of the group can be more specific.

It was noted that the list of functions does not include anything related to consumer perspective. Some language could be added to link this to consumer advocacy if that falls under the functions of the Consortium. This type of language has been added to Consortium products at times and would be consistent with the education philosophy of the Consortium and that of Consortium member organizations. One goal of this group will be to have conversations with consumers to help them understand why it is necessary to collect data and how we can protect the data that we collect. Dorothy will work on some language to add to this list of functions.

Members also wondered if a function of this committee might be to establish some mechanism to review and qualify the types of technology that will support standards. Many vendors are creating technological products, but the average provider or public health entity does not have a way to assess or compare such products. Perhaps this committee could develop some criteria that could be used to compile a list of vendors and the type of technology they have developed. Putting out this type of information is very difficult for government agencies, but would be very helpful for other entities. Over the past year, SAMHSA developed a list of vendors and reviewed some of their products and some pricing information. The plan is to put this list out on their website with a search engine to enable consumers to obtain this information and vendors to submit products. The list is broken out into HIPAA, Privacy, Security, and Transactions and then further to Foundations, Government, Federal Government, and Public Domain. The list was used as part of a book put out for training conducted last year. Over 600 vendors were listed and at least two products for each vendor were reviewed. Although the descriptors for each product are actually from the vendors, the sales language was eliminated. Recent hearings by the NCVHS about privacy indicated that people want to know about vendors. There is no way to certify vendors, but some guidance would be very useful. This workgroup could be instrumental in looking at innovation in technology and could point our clients to white papers and evaluation tools and lists that could be vendor neutral. All of this would work well with the Web-based Resource Center being developed by PHDSC.

A committee member asked if NCVHS would be having panel testimony on the subject of unique identifiers for individuals. One company has developed an algorithm that cuts data in several ways and significantly reduces the risks for re-identification. While there are no algorithms that work perfectly, it may help NCVHS to understand the need in research for a unique identifier in order to link data systems. Other committee members expressed concern and felt that a priority area should be to expand on efforts being made in the education of all concerned parties about the HIPAA Privacy Rule. The science for technological solutions remains controversial and may not address fundamental issues related to the use of protected health information in Public Health. A better understanding of the privacy regulations is an essential first step that has not yet been adequately addressed. This area has been ignored to date due to complexity of the rule and modifications that were not finalized until August of 2002. Few people are comfortable in their understanding of the HIPAA privacy regulation. The PHDSC has enormous resources within our member organizations. A major threat to public health and health services research is that a lack of education will lead to reduced access to essential data. It is anticipated that some data holders will be reluctant to provide even mandated data and to cooperate with public health data systems and researchers. The PHDSC can work through its member organizations to look at the most important concerns and develop our niche to address them.

The group looked at the listing of overall functions to see how we could develop a work plan. The e-health initiative held a conference regarding privacy in which we were unable to participate. We might just make members more aware of this type of meeting, but we could potentially do more. Much work remains to educate entities and IRBs. Workgroup members are to identify changes they would like to see in these overall functions and draft change language. Comments will be posted to the listserv for all to review. The group approved adoption of these objectives and functions subject to any comments that may come in from the group.

The workgroup also identified that there is a potential partnership with OCR to conduct educational outreach activities – particularly to public health. A group of agencies have been working with OCR through an interagency agreement to create materials. A general booklet and a number of fact sheets in various areas are being created. Because research and public health are not seen as covered entities, they have not been targeted as a priority for outreach. This workgroup feels that it is critical to get information out to them. The FAQ document has been released from OCR and will be up on several websites with links to other federal agencies. The PHDSC could be instrumental in getting the word out to our member organizations about these materials and then solicit feedback about the public health questions that are not answered by the document. Ultimately, the PHDSC could assist OCR in creating materials specific to public health. Members were encouraged to read the OCR guidance and comment specifically about what might have been missed in these initial materials. OCR may not have developed a mechanism to address the concern that covered entities will curtail the flow of information to research entities. The PHDSC could work on ways to address that issue. DHHS has a vested interest in research and OCR has clearly made an effort to address challenges that the privacy Rule has presented for researchers. This committee should investigate some partnership with OCR to use our member organizations to educate providers and the public.

Discussion About Questions for Kathleen Fyffe, OCR's HIPAA Privacy

Kathleen Fyffe will be attending our annual Steering Committee meeting. If the workgroup wants to ask her specific questions, we should get those questions to her before the meeting. Michelle will notify her that we will be doing this. Workgroup members are asked to look at the guidance on the web site and develop a list of questions that are not addressed by the guidance. These questions should not be personal questions, but should be specific in scope and should suggest a potential approach for her concurrence. OCR may know of work being done elsewhere, which could provide partnership opportunities. OCR may also be aware of issues or needs that they are currently unable to pursue. The workgroup could offer assistance in focusing on areas that have not yet been addressed. The outcome of this session with OCR should be development of three to four things that this workgroup can do that enhances but does not duplicate the work of other groups or agencies.

A workgroup member mentioned that the letter sent by NCVHS indicated the need for standardized forms, such as data use agreements. There are a number of templates out there and this workgroup could be useful in reviewing these. Again, the workgroup could put together our concerns and suggestions to alert OCR that the Consortium is a resource. We could also be instrumental in evaluating whether the privacy rule is negatively impacting the collection of data. This evaluation could help shape the privacy rule as it evolves over time. It was suggested that perhaps Mike Fitzmaurice could be invited to participate in the discussion for an additional perspective.

Updates on current activities

The Academy for Health is conducting two one-day workshops—one in San Francisco and one in Washington DC—for health researchers to prepare them for the rule and to know how to work with IRBs. They should come out of these workshops with suggested practices and mechanisms for them to proceed with health research when they need to go through this process, and will have one or two standardized forms and tools such as authorization forms and data use agreements for their use. Workgroups then break out to review a case study format and determine how the rule will impact such work. These workgroups could create modules that could be made available to people through a variety of websites and could link to the WRC. These could also be used to create tutorials for use as an ongoing resource.

AHRQ has been working with NIH, FDA, CDC, OHRP and OCR to create a series of educational materials on the HIPAA Privacy Rule. Discussion has begun at AHRQ about longer term plans to fund research on the effects of the regulation on the research on health services research.

Next Steps, i.e., conference calls, annual Steering Committee meeting, projects

The PDSC workgroup will make a report at the annual meeting on March 13. The report time slot is 15 minutes, with a 10 minute presentation and 5 minutes for questions. It is scheduled for the first day of the meeting.

The next call will be scheduled soon after the holidays. We will plan on one call in January and one in February to prepare for the meeting. In the meantime, workgroup members are asked to consider how this workgroup can collaborate with

other workgroups of the Consortium. Perhaps the material from the Academy workshops could be packaged for inclusion on the WRC. Another suggestion is to work with the reporting guide workgroup to help educate covered entities about continuing to report to public health and potentially using this guide to conduct such reporting.

John will work on a draft of a work plan for this workgroup and will circulate that to the listserve for comment. A simultaneous document editing feature can be used to work on this document collaboratively over the web. Dorothy will see to arranging this.

Dorothy also suggested adding the following language to item #4 in the function list, ". . .including public health and health services research professionals, consumer advocates, and privacy & security technology specialists." The group agreed to this language.

Action Items:

*workgroup members to review the NCVHS letter to Secretary Thompson for potential functions for this committee.

*workgroup members to review the OCR guidance to develop questions related to what has not been addressed for public health and research and frame those questions with suggestions for solutions to submit to Kathleen Fyffe at the Steering Committee meeting.

*workgroup members to submit suggestions for changes to the charter document to the listserve.

*workgroup members to make suggestions regarding how this workgroup can partner with existing workgroups of the Consortium and provide value to products already underway.

*John to begin a draft of the work plan to submit to the listserve

*Dorothy to arrange for simultaneous document editing web feature so the group can complete their work plan.

*Michelle to contact Kathleen Fyffe to notify her of how we will be asking questions during the annual meeting.